

# "One of My Better Operations"

## Older Women and Cancer

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*Ce texte reprend les recherches d'une étude sur des femmes de 70 ans et plus chez qui on a diagnostiqué un cancer du sein ou un cancer gynécologique. Les participantes ont avoué qu'il n'y avait rien là. L'auteure ne le perçoit pas ainsi et elle assure que ce message peut être trompeur. Au niveau de la personne, ce n'est pas un signe d'indifférence au cancer, mais socialement, de multiples facteurs qui, combinés reflètent ou répriment la souffrance chez les femmes plus âgées.*

It all began with a kind of puzzlement. Ann and Thelma and Enid, members of our research team, had each interviewed five women aged 70 and older about their experiences of cancer and cancer care. When we gathered to review the transcripts, some of the women's words surprised us. We started to hear the message that cancer was "no big deal," not especially disruptive or distressing. This was a storyline very different than the one we were familiar with, very different too from the literature we had read: the sociology of health and illness has its own special term, biographical disruption (Bury), to describe the profound shaking up of a life story that serious illness supposedly causes.

The women's words thus captured our attention. Do women in their 70s and 80s really experience cancer as "no big deal"—as biographically

"undisruptive?" If yes, why? And our standard social science question: is there anything else going on here?

We went back to the transcripts, and read them again, and the interviewers went off a second time, to talk again with each of the women who participated in the study. They asked more questions about exactly these sorts of statements, these "no big deal" messages. This article is an account of what we learned.

At 77, Becky is solely responsible for the care of her disabled adult son. Her son cannot be left alone, and his care needs are increasing. Thelma asked Becky about the "worst things" that happened over the course of her cancer diagnosis and treatment, and this is what she said:

*The only time I was a little distressed was I had to wait two hours for my appointment. [laughter] 'Cause I don't have that kind of time... I get a little bit antsy when I have to be away [from my son] for two hours and not arranged for being away for two hours, you know?*

Marie, diagnosed with breast cancer at 81, said this:

*To be honest with you, I don't... I forget I have cancer because my eyes are the ones that bother me. I'm terrified I'll go blind.*

*I'm terrified... I can't see out of this one at all, but I see a little bit out of this one. And I'm to go back to have a cataract taken off. That part's nothing. But I sit here sometimes and I think "what if some little thing happened to this eye, I'll be really blind."*

From these kinds of conversations, we learned that cancer diagnosis sometimes recedes in significance in relation to more pressing health and life problems.

Several of the women we interviewed used versions of the phrase "it could be worse" to describe cancer's effect on their lives. "It could be worse" was sometimes a comparison with children who had cancer, or young parents in a cancer centre waiting room. But more commonly the "worse" situation was not imagined or speculated about. Instead women's knowledge of "the worse it could have been" came out of their own histories of caring for someone who had a serious illness, often their husbands or partners. As Becky said, "after a whole year at the hospital with [husband], why three operations ... mine seemed insignificant." "My husband had been ill for some time," said Lisa, "I've wondered if I could have done what he did. He was looking at that for 15 years."

Therefore, we learn here that cancer and cancer treatment often receded in significance for participants, got

smaller as a life event, *when it was set against* past, current, or anticipated health and social problems (their own or those of people close to them).

The significance of cancer treatment also sometimes faded when it was set against very difficult medical interventions in the past. Freda spoke, for instance, about the surgery that removed a tumour on her scalp many years prior:

So the older women who took part in our study have some common ground with younger women who have had lots of hardship packed into their fewer years.

For women in the 70+ study, having lived for many years, and especially having had to overcome things and figure things out, also lent perspective, knowledge and strength for responding to cancer. Freda, for

strength not to cry about things; we return to this point below.

We should make clear that this is not the whole story. There were moments—less common, but definitely present—when the women we interviewed talked about cancer as a big deal and in fact said that older age made cancer worse in some ways. For the full study findings, see Sinding and Wiernikowski, 2008).

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## When set against past, current, or anticipated health and social problems, the significance of cancer receded. This does not mean that the women were indifferent to cancer. Rather, we learned how other “big deal” life events can, for some women in some circumstances, overshadow a cancer diagnosis.

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*In the old days the butcher used to hold a wire brush to clean his counters, you know, and that's what it felt like ... and then I must have passed out. And then when I woke up, I woke up with shock. They'd given me resuscitation.* (Freda, diagnosed at 87)

Against experiences like this, Freda described cancer as “a big deal to others but not to yourself.” In a similar way, Martha, diagnosed at 74, said the mastectomy was “one of [my] better operations.”

As we started reading more, we learned that other researchers had come across these sorts of “no big deal” stories. Ciambrone interviewed women who had been diagnosed with HIV who had also lived through violence, drug addiction, and separation from their children. One of the women described HIV infection as “a piece of cake [compared to] living with an abusive person” (523). In another study, a man living in poverty was asked about the effects of stroke on his life, and he replied, quite simply, “I'm starving” (Pound et al. 499). So here again we see that the disruption of illness can pale in relation to the persistent struggle and frequent crises of daily life that come with poverty and social marginalization.

instance, had experienced four major surgeries in her past, and said she “didn't get worked up” about having surgery to remove her breast: “I say to myself, where else?” Lisa referred to “various emergencies with three sons,” noting that “through the years you gather a little bit of information.” Lisa suggested, in fact, that younger people might require more guidance about illness and recovery than she, with her accumulated knowledge and resourcefulness, did. Rosy, reflecting on the ways she handled her cancer diagnosis, described an abusive relationship with her first husband:

*That's all he does—just wants to hurt you all the time. So I cry all the time and the kids come along. But you know what? After I split up with him, I was shocking myself. I became the strongest person in this whole world. And no more cry, no more tears... I became so strong and so independent myself.* (Rosy, diagnosed at 72)

Over their lifetimes, then, older women seem to gather perspective and skills, information and strength for dealing with cancer. Of note here however is that Rosy speaks of gaining strength not only to cope with subsequent hardship, but also

For the most part however, the women who took part in this study suggested that the experience of cancer was eased by resources developed over many years of living. As well, when set against past, current, or anticipated health and social problems, the significance of cancer receded. This does not mean that the women we interviewed were indifferent to cancer. Rather, we learned from this study how other “big deal” life events can, for some women in some circumstances, overshadow a cancer diagnosis.

So far we have written about how older age, and histories of illness and hardship, shape how women experience cancer. We are going to turn now to another way of understanding this “no big deal” message we heard from the women we interviewed. And it has to do with how older women talk about hardship—and especially, their deep commitments to not dwell on bad things.

Assertions about not attending to (not thinking about, not worrying about, not dwelling on) cancer appeared in the majority of the interviews in this study:

*They do say that there's a possibility of it coming back somewhere else but I'm not worried about it... I know some people*

*who worry themselves sick over something that never happens. (Peggy, diagnosed at 78)*

*If you read all the literature that you get and you think about it... the more you think about it the worse it gets. (Loretta, diagnosed at 87)*

*I think sometimes people worry.... If they get into it too deeply, some people fall apart. (Lisa, diagnosed at 81)*

In these quotes, participants seem to be saying that focusing on cancer (and problems generally) carries certain risks, that it is bad for you. What is good for you, it seems, is “keeping busy”

*I think with any sickness whether cancer or what, keep busy.... that's why I joined the bridge clubs and everything because it's a salvation. It gets your mind off. (Brigit, diagnosed at 86)*

*I try very hard not to think about it [cancer and possible recurrence]. (Loretta, diagnosed at 87)*

*[Cancer] is big in your mind, in your life, especially if I sit and don't do nothing, sometimes I feel like I go out of my mind, but I try to keep myself busy all the time. (Rosy, diagnosed at 72)*

Here dwelling on things is to be resisted by activity; the mind must not rest on difficulties; social and physical engagement and motion offers the benefits of a mind distracted from difficulties, and intact.

In addition to suggesting that “not dwelling on things” was a wise and healthy approach, women also claimed that focusing on cancer, its treatment, and the threat it represented, was pointless:

*Enid: It sounds like you weren't told what to expect [around the mastectomy]*

*Alice: They probably told me and I probably ignored it. [laughter]... If they're going to do it, why worry about it? (Alice, diagnosed at 77)*

*I didn't expect [health professionals] to do a whole lot because [if I have] the operation, then if they gave me medication, then what else can they do? ...I don't really think about it, let's put it that way. I know I have it and I know it's there, and maybe I'll get some more of it. But what can I do about it? I just have to rely on the doctors and take my medication. (Loretta, diagnosed at 87)*

*I don't dwell on [cancer] and I don't think ahead because who knows? Nobody knows. And I don't chew over yesterday or the day before that or the years before that because it does no good. You can't change a thing, right? (Martha, diagnosed at 74)*

At some point during this study we started to think about what these sorts of quotes meant in the bigger picture, in the really big picture of women's lives. Not focusing on cancer (not worrying about, “chewing over”, thinking about life difficulties) seemed to be rooted in experiences of relative lack of power. The process of mastectomy might be unknown, cancer might recur, but, these women said, the doctors are going to do what they do, what can I do about it, you can't change a thing, right? In part, of course, their comments acknowledged the inevitability of some biological processes, and the limitations of medicine. Yet they also appeared to reflect *social* experiences. Thelma, when she interviewed Becky the second time, asked her if she would encourage other women to seek out health professionals who explain things well. Becky said: “Yeah, but then you have to go with who you're given, I guess, or whatever. The powers that be make your decision that way.”

So according to these women, the only things worth focusing on are things that can be changed. And it also seems that the scope of what is available to them to change is quite narrow.

*As researchers we often learn from our own responses to what participants are saying. I don't experience my world in the terms that Martha does here—“you can't change a thing.” And when there are things, difficult things, that I really can't change, I sure talk about them. So this disjuncture between how I think and talk about the world, and how these women think and talk about the world, alerts us to important differences in how women experience and discuss health problems—differences that have to do with age, generation and life circumstance, and probably also social class—Chris.*

Let us say a bit more about how “not dwelling on things” was linked in this study with social circumstances. Becky explained her approach to cancer in relation to the demands of caring for her disabled son: “When I have a problem, I just forget about it. It's gone, and I go on to the next, ‘cause it seems as if every day there's another one.” In the course of a conversation about how her cancer was detected, and the time between her diagnosis and surgery, Becky said this:

*Becky: [The lumps] were so small, they could hardly see them, you see—*

*Thelma: You had more than one lump?*

*Becky: I think he said two. But you see, I never paid attention because I was busy getting on to the next part of my life, that I wasn't going to dwell on it and I don't dwell on it. ...*

*Thelma: I was just curious to know about that waiting period...how did you feel about that when...*

*Becky: I don't feel about anything like that. When it has to come along...I take each day. I don't look ahead and I don't go back... That might not be the*

*way to do it but it's the only way I've been able to survive.* (Becky, diagnosed at 75)

In not focusing on the details of her diagnosis, and in “not feeling” about the wait or the upcoming surgery, Becky expresses in extreme terms a common theme in our interviews. Out of experiences of relative powerlessness to influence life problems, some women

*think it's just like having a tooth out and forget about it. No, it's not like that... [My husband] thinks that, you know, it isn't all that bad... You know, it's over and done and you forget it.* (Martha, diagnosed at 74)

Younger cancer survivors also talk about feeling that their partners or children want them to “get over”

cancer—and we also wanted to know why they said what they did. In our research we learned about the contexts of older women's lives, and how these contexts shape how women experience and talk about cancer. We learned that when really difficult life circumstances are “taken into account,” cancer can be overshadowed. And we also realized that sometimes, it is exactly the context—those issues

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simply do not focus on them, and they certainly don't talk about them.

So what do we learn here? Even if cancer was felt to be a really a big deal—these quotes tell us that we simply might not hear about it.

And here is the other layer: women got lots of positive reinforcement for saying or acting as if cancer was no big deal, and some negatives when they did focus on it. Lisa said, in the first weeks after diagnosis, “you can get a little ... maudlin ... and people aren't interested in listening to that. To a point but ... and they care, but you can be a bore.” She felt her family was “happy ... that I don't get into details.” Brigit described her bridge club as a salvation because it kept her mind off her problems. In explaining her commitment to keeping busy, she also noted that “nobody wants to sit and listen to your problems.” Concerns about being perceived as a whiner, a complainer, a bore, and the sense that other people “don't want to hear about it,” threaded through respondents' accounts. Asked if she might have welcomed an opportunity to talk with someone about her feelings about cancer, Martha responded:

*Well, I would say so. I think it would be good because you know you feel all alone. Some people*

their experience of cancer (Sinding and Gray). But they rarely feel the need to assert that a cancer diagnosis is more difficult than dental work. Minimizing the significance of cancer may indeed be understood by older women as the healthy way to approach the illness. At the same time, it appears they experience some pressure to deal with it that way.

So from this study we can learn that older age shapes not only how women experience health problems, but is also significantly implicated in how women talk about health problems (Charles and Walters).

Let's take a step back, look at the big picture again. We saw in the early quotes this message that cancer and cancer treatment is “no big deal.” One of the problematic interpretations of these “no big deal” messages is that older women diagnosed with cancer don't need or want support—and this is the conclusion that some researchers have reached. In at least one study that we reviewed, finding that elderly cancer patients report less psychosocial disruption than do younger patients, researchers suggested that interventions be redirected, towards younger patients.

Our research points in a different direction. We wanted to know what older women had to say about

that are being “taken into account,” these “overshadowing” factors—that require attention and action.

So for instance, Lisa and Marie worried that they wouldn't be able to continue living at home. And Becky faced the demands of caregiving, and Rosy the ongoing strain of not having enough money. We can understand these as personal worries and difficulties—and, we can understand them as social problems. Worries about being able to live at home, and about being able to provide care for disabled family members, are directly linked to the adequacy of homecare services. The worries and tradeoffs that come with not having enough money are created by inadequacies in income support programs.

Of course we care about older women being well supported in the community, period. But as cancer advocates, we have a special interest: *because it is in part the absence of these social supports, creating such strain and worry about daily living, that lead older women to talk about cancer as “not a big deal.”*

Let us say a bit more about this. Four of the women we interviewed chose not to have a treatment that had been recommended to them. Lisa, for instance, in spite of the doctor's recommendations, chose not

to have chemotherapy. This is how she explained her decision:

*Quality of life with chemo didn't appeal to me at all. I live alone, I like it and I know many people who have gone through it and depended on whoever's handy ... I know my hairdresser told me about her friend and his children abandoned him and he, of course, didn't have much to eat even.*

When Lisa was making her decisions about treatment she was taking into account the kind of support she could expect at home. Her choice, while at some level a personal one, occurs within a broader social context: in the last several years public funds for home care have been severely curtailed and disparities between people who have access to family support or private services and those who do not are widening (Aronson and Neysmith). Lisa is right that older people are increasingly depending on "whoever's handy" for care.

Home care, income support—these things don't seem centrally related to the experience of breast cancer. But we can see in this study how, when worries about money or caregiving or being able to remain at home are top of mind, many older women with cancer do not (allow themselves to?) think about, or talk about, struggles with cancer. Sometimes these social factors even enter into the choice to forego treatment. In our community groups and as advocates, as service providers and survivors, we must do our part to make sure older women are well supported in the community. It may not be as obvious, but this, too, is breast cancer activism.

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